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# Gender and the Premature Deaths of People with Intellectual Disabilities: An International Expert Consultation

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## Abstract

People with intellectual disabilities die at much younger ages than the general population, with this gap in life expectancy greater for females than males. This study aimed to seek the views of international experts concerning evidence relating to gender and the premature deaths of people with intellectual disabilities, their views on priorities for future research, and recommendations for future research and policy. Twenty international experts on the health and/or mortality of people with intellectual disabilities were invited to complete an online questionnaire. The questionnaire was based on summary statements from a literature review on gender and premature death among people with intellectual disabilities compared to the general population. Summary statements included general topics such as mortality and specific major causes of death (e.g., cancer). For each summary statement, respondents rated on 5-point scales: their agreement with the statement; the importance of the topic; and the adequacy of the evidence. Participants then indicated their top three priorities for future research, and gave recommendations for future research and policy. Eighteen (90% response rate) respondents from nine countries participated. There was consensus among respondents regarding the greater inequality in intellectual disability vs. general population mortality rates for women compared to men. Evidence was considered inadequate for most topics. Evidence on cause-specific death rates was the most frequently mentioned main research priority, followed by age trends in mortality compared to the general population. Recommendations ranged from the need to use consistent methodology and case definition in future research, to the need for governments to be called to account on the issue. Further evidence on gender and mortality is urgently needed; an international consensus on recommendations for future research pertaining to gender and the premature deaths of people with intellectual disabilities would greatly assist the development of evidence-based policy and practice.

**Keywords:** expert consultation, gender, intellectual disabilities, mortality, review

## Introduction

People with intellectual disabilities die at much younger ages than the general population. For example, life expectancy at birth in England is nearly 20 years lower for people with intellectual disabilities than for people without intellectual disabilities (Glover, Williams, Heslop, Oyinola, & Grey, 2017). In the general population women on average live longer than men, whereas for people with intellectual disabilities women and men tend to die at similar (much younger) ages. Therefore, the gap in life expectancy between populations with and without intellectual disabilities is greater for women with intellectual disabilities than men with intellectual disabilities. This is a consistent

finding across a number of high income countries. For example, the Confidential Inquiry into premature deaths of people with intellectual disabilities in England found that males and females with intellectual disabilities lived to a similar median age 65 and 63 years, respectively, with males with intellectual disabilities dying 13 years earlier than the general male population of England and Wales, and females with intellectual disabilities dying 20 years earlier than the general female population (Heslop et al., 2014). An Australian study found that the median age at death was 23 years earlier for men with intellectual disabilities than men in the general population and 32 years earlier for women with intellectual disabilities (Trollor, Srasuebku, Xu, & Howlett, 2017). In Finland, the average age at death of people with intellectual disabilities was found to be 22 years younger for men and 30 years for women (Arvio, Salokivi, & Bjelogrić-Laakso, 2017) compared to their general population peers. A recent systematic review of early death and causes of death among people with intellectual disabilities found that

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standardized mortality rates showed a greater inequality for women than men (O'Leary, Cooper, & Hughes-McCormack, 2018).

Reasons for this different pattern of mortality by gender relative to the general population are unclear. Understanding the nature of the differential gender patterns in mortality for people with intellectual disabilities compared to the general population may help to more effectively direct research, policy, and practice seeking to reduce premature mortality among people with intellectual disabilities. This study aimed to present the views of international experts on the evidence base relevant to understanding these differences in mortality by gender for people with intellectual disabilities compared to the general population. In order to facilitate the international expert consultation, a broad literature review was conducted to summarize evidence on gender and mortality, as well as evidence on gender issues in relation to health conditions commonly related to causes of death among people with intellectual disabilities ([http://www.research.lancs.ac.uk/portal/en/publications/gender-and-the-premature-deaths-of-people-with-intellectual-disabilities\(60899884-1210-4cc2-9d1b-4f1dcb4cab28\).html](http://www.research.lancs.ac.uk/portal/en/publications/gender-and-the-premature-deaths-of-people-with-intellectual-disabilities(60899884-1210-4cc2-9d1b-4f1dcb4cab28).html)).

The review outlined evidence regarding gender differences in mortality among people with intellectual disabilities compared to the general population. The review then summarized evidence on gender differences in health conditions (and external causes of death) related to mortality among people with and without intellectual disabilities, including respiratory disease, cancer, cardiovascular disease, dementia, epilepsy, diseases of the digestive system, infectious diseases, endocrine disorders and diabetes, and bone health and fractures. Next, the review summarized evidence on gender-specific issues such as testicular, breast, and cervical cancer. Evidence was also presented on gender differences in risk factors for common causes of death such as obesity, physical inactivity, and metabolic syndrome. Finally, evidence was presented in relation to some specific syndromes such as Down syndrome and Rett syndrome.

For each topic in the literature review, a summary statement was formulated. For example, for "age at death" the summary stated that: "The gap in life expectancy between those with intellectual disabilities and the general population is greater for females than males" (see Table 1 for a complete set of summary statements).

The overall aim of the international expert consultation was to inform further research, policy, practice, and health promotion designed to tackle premature deaths among men and women with intellectual disabilities. The consultation sought the views of experts on: (1) the content of the literature review (agreement with the summary statement, importance of each topic, strength of the evidence); (2) priorities for future research relating to gender and the premature deaths of people with intellectual disabilities; and (3) suggestions on how gaps in the evidence base could be addressed.

## Methodology

### Literature Review

A review of international literature regarding gender and the premature deaths of people with intellectual disabilities was

undertaken in 2018/19. Literature was sought including both peer reviewed literature and other data or reports (such as public health/surveillance reports). Literature published from 1990 to November 2018 in the English language was included. Electronic literature database searches (Medline, Cinahl, and PsycInfo) used terms for intellectual disabilities as employed in published systematic reviews (Robertson, Chadwick, Baines, Emerson, & Hatton, 2017; Robertson, Hatton, Emerson, & Baines, 2015). These were combined using the Boolean operator "and" with terms for mortality or specific health conditions which constitute the major causes of death for people with intellectual disabilities (O'Leary et al., 2018), and terms for gender. Final searches were undertaken on November 27, 2018. A request for information relevant to the review was also sent via email to the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Health Special Interest Research Group (SIRG) and the Intellectual Disability UK Research JISC mailing list (managed by Prof. Richard Hastings at Warwick University, with 358 subscribers) in November 2018. The literature review was used to prepare summary statements regarding gender issues in relation to the premature deaths of people with intellectual disabilities. The literature review is available in the [http://www.research.lancs.ac.uk/portal/en/publications/gender-and-the-premature-deaths-of-people-with-intellectual-disabilities\(60899884-1210-4cc2-9d1b-4f1dcb4cab28\).html](http://www.research.lancs.ac.uk/portal/en/publications/gender-and-the-premature-deaths-of-people-with-intellectual-disabilities(60899884-1210-4cc2-9d1b-4f1dcb4cab28).html) for this article, and the summary statements are presented in Table 1.

### International Expert Consultation

The literature review and summary statements formed the basis of a structured online questionnaire created using Qualtrics software (Qualtrics, Provo, UT; [www.qualtrics.com](http://www.qualtrics.com)). The online questionnaire was pilot tested by three collaborators within the IASSIDD Health SIRG, with amendments being made following pilot testing. The questionnaire provided respondents with statements summarizing the evidence regarding gender and premature death under specific topic headings as used in the literature review, including mortality compared to the general population, age trends in gender differences in mortality, age at death, specific major causes of death (e.g., cardiovascular disease, cancer, and respiratory disorders), risk factors for common causes of death (e.g., obesity), and gender specific issues (e.g., prostate, testicular, breast, and cervical cancer). Cause-specific mortality rates by gender were subsumed within the section for each specific cause of death where available.

For each topic, the structured questionnaire asked respondents to rate three questions on five-point Likert scales (strongly disagree (1) to strongly agree (5)): Q1 "To what extent do you agree with this statement?," Q2 "To what extent do you agree that this is an important topic?," and Q3 "To what extent do you agree that the evidence base on this topic is adequate?" Each topic included an open-ended question inviting respondents to comment. Following pilot testing, the topics were divided into "core" topics which all participants were requested to respond to, and "optional" topics which respondents could answer if

TABLE 1  
Topic summary statements

<b>Mortality</b>	
Age at death	The gap in life expectancy between those with intellectual disabilities and the general population is greater for females than males.
Age trends in gender differences in mortality	The greater inequality in mortality rates for females with intellectual disabilities is mainly a feature of younger age groups.
Gender differences in mortality compared to the general population	While there are some conflicting results, the weight of evidence suggests that inequality in mortality rates between the population of people with intellectual disabilities and the general population is greater for females than males.
Health condition related to mortality	
Bone health and fractures	Older women with intellectual disabilities may be more at risk of fatal fracture than women in the general population. Poor bone health and fractures appear to be more common among women with intellectual disabilities than men. However, men with intellectual disabilities are also at increased risk of poor bone health and fractures compared to the general population.
Cancer	There is little evidence relating to gender and the risk of death due to cancer in people with intellectual disabilities. Some studies report no association with gender. Deaths from cancer in those with intellectual disabilities may occur at a younger age than in the general population, especially among women. While gender differences have been reported with regards to the risk of specific types of cancer among people with intellectual disabilities, evidence is insufficient and further research is required to confirm these findings.
Cardiovascular disease	There is little evidence on gender differences in the risk of death from CVDs. Evidence regarding gender differences in the prevalence of CVDs is mixed, with some studies suggesting that women with intellectual disabilities are more at risk, and other studies finding no evidence of a gender difference. For those newly initiating antipsychotic medication, being female appears to be associated with a greater risk of venous thromboembolism.
Dementia	There is very little evidence on gender differences in the risk of death related to dementia among people with intellectual disabilities. Women with intellectual disabilities appear to be at greater risk of having dementia than men with intellectual disabilities.
Diabetes	We are not aware of any evidence on gender differences in the risk of death due to diabetes among people with intellectual disabilities. Women with intellectual disabilities appear to have a higher prevalence of diabetes than women in the general population, particularly noninsulin dependent diabetes, but this has not been found for men with intellectual disabilities. A high prevalence of being overweight among women with intellectual disabilities may be an explanation for their higher prevalence of non-insulin-dependent diabetes mellitus.
Digestive system	Evidence on gender differences in the risk of death due to diseases of the digestive system is limited and conflicting. There is also limited and conflicting evidence regarding gender differences in the risk of digestive system disorders among people with intellectual disabilities.
Endocrine disorders (diabetes is dealt with as a separate topic)	We are not aware of any evidence on gender differences in the risk of death due to endocrine disorders. Endocrine disorders have been reported to be more common among women than men with intellectual disabilities but the evidence is limited. There does not appear to be any evidence comparing the risk of endocrine disorders among men and women with intellectual disabilities to men and women in the general population.
Epilepsy	The extremely limited evidence suggests that there are no gender differences in the risk of death due to epilepsy among people with intellectual disabilities. One study suggests that all-cause mortality may be higher for women than men with

(Continues)

TABLE 1  
Continued

<b>Mortality</b>	
	intellectual disabilities who have epilepsy. Overall there is no strong evidence to suggest that the prevalence of epilepsy varies between men and women with intellectual disabilities.
Death from external causes	Men with intellectual disabilities are at less risk of death from external causes than men in the general population. However, the limited available evidence suggests that the mortality disadvantage of females with intellectual disabilities cannot be completely attributed to the differential pattern of mortality in relation to external causes of death.
Infectious diseases	The small amount of evidence on the risk of death from infectious diseases among people with intellectual disabilities shows no gender difference. The little evidence available suggests that older women with intellectual disabilities may be more likely to suffer from infectious diseases than men. This may be related to an increased risk of urinary tract infections. Further research is required to confirm these findings.
Respiratory disease	There is not enough evidence to make conclusions about gender differences in the risk of death due to respiratory disease. Some evidence suggests that men aged over 40 with intellectual disabilities may be less likely to have respiratory diseases than women but further evidence is required to support this finding.
Specific syndromes	
Down syndrome	Limited evidence suggests that the survival advantage for females seen in the general population might not be evident for females with Down syndrome. Evidence is consistent in indicating that females with Down syndrome are more likely to have congenital heart disease than males. Further evidence is required regarding gender and cancer in people with Down syndrome. Few studies have examined the risk of dementia separately for men and women with Down syndrome. Women with Down syndrome may be at increased risk of diabetes. Poor bone health and fractures are common among women with Down syndrome and this is also a significant issue for men with Down syndrome.
Fragile X syndrome	Females with Fragile X syndrome tend to be less severely affected than males, for example, they are less likely to have epilepsy. However, there is little specific evidence comparing the health and mortality of males and females with Fragile X syndrome.
Prader Willi syndrome	Males with Prader Willi syndrome may be at higher risk of early mortality than females. Males may be more at risk of accidental death and choking. Cardiopulmonary and BMI-related mortality factors may predominate among females.
Rett syndrome	Rett syndrome almost exclusively affects females. Survival for those with Rett syndrome is lower than for those in the general population. Respiratory related conditions are the main cause of death. They are vulnerable to lower respiratory tract infections requiring hospitalization. Epilepsy is highly prevalent and may be uncontrolled. A high prevalence of epilepsy and scoliosis may increase vulnerability to respiratory infections. Autonomic nervous system dysregulation makes those with Rett syndrome vulnerable to sudden cardiac death. There may be subclinical myocardial dysfunction and unrecognized lung disease. Poor bone health and fractures are common among people with Rett syndrome.
Male specific issues	
Prostate cancer	We are not aware of any evidence on the risk of death due to prostate cancer among men with intellectual disabilities. The small amount of evidence available suggests that the incidence of prostate cancer among men with intellectual disabilities may be lower than that of men in the general population. However, it is not clear to

(Continues)

TABLE 1  
Continued

<b>Mortality</b>	
	what extent this reflects a lack of screening among men with intellectual disabilities.
Testicular cancer	The little available evidence suggests that men with intellectual disability may be at greater risk of death due to testicular cancer than men in the general population. Men with intellectual disabilities may be at increased risk of having testicular cancer, particularly those with Down syndrome. Among men with Down syndrome, testicular cancer is more often identified at a late stage. Men with intellectual disabilities who have testicular cancer are far more likely to die than men with testicular cancer in the general population.
Female specific issues	
Breast cancer	There is little evidence on the risk of death due to breast cancer among women with intellectual disabilities. Evidence on the incidence of breast cancer is inconsistent. Women with intellectual disabilities may be at risk of delayed diagnosis which can adversely affect outcomes. Risk factors for breast cancer are common among women with intellectual disabilities but they are less likely to be in receipt of breast screening. Women with Down syndrome and Fragile X syndrome are at lower risk of breast cancer than other women. Women with other genetic conditions associated with intellectual disabilities, including neurofibromatosis 1, may be at increased risk of breast cancer.
Cervical cancer	We are not aware of any evidence on the risk of death from cervical cancer among women with intellectual disabilities. The prevalence of cervical cancer is lower in women with intellectual disabilities than other women but the risk is not negligible. Women with intellectual disabilities are less likely to receive a cervical screening test than other women, sometimes on the basis of their assumed lack of sexual activity.
Contraception	Women with intellectual disabilities have different patterns of contraceptive use to women in the general population, with greater use of long-acting contraception such as contraceptive implants or injections. There is a disproportionate use of Depo-Provera among women with intellectual disabilities which may reduce bone mineral density and cause weight gain. Women with intellectual disabilities may be prescribed contraception when they are not sexually active "just in case" or to manage menstruation.
Menopause	Women with intellectual disabilities, and in particular women with Down syndrome, tend to have earlier menopause than other women. In women with Down syndrome, early age at menopause has been found to be associated with an increased risk of dementia and with risk of death.
Ovaries and uteri cancer	There is very little evidence on the risk of death due to cancer of the ovaries and uteri among women with intellectual disabilities. Evidence regarding the incidence of cancer of the ovaries and uteri is mixed, with some evidence suggesting that incidence may be higher among women with intellectual disabilities than women in the general population, but other evidence indicating no difference.
Pregnancy and childbirth	We are not aware of any evidence on the risk of death in relation to pregnancy and childbirth among women with intellectual disabilities. Women with intellectual disabilities experience poorer maternal wellbeing and pregnancy outcomes compared to the general population. This includes increased rates of pre-eclampsia, venous thromboembolism, pre-term birth, delivery by caesarean section, and higher rates of postpartum hospital admissions and emergency department visits. Services may not offer appropriate support to meet the needs of pregnant women with intellectual disabilities.

(Continues)

TABLE 1  
Continued

<b>Mortality</b>	
Risk factors	
High cholesterol	There is little evidence regarding gender differences in relation to high cholesterol in people with intellectual disabilities. Studies based on recorded diagnoses present conflicting findings but high cholesterol is likely to be underdiagnosed. More studies based on blood testing are required to clarify any gender differences and the age related nature of any differences.
Hypertension	Both men and women with intellectual disabilities have been reported to be less likely to have a diagnosis of hypertension than men and women in the general population. However, hypertension may be underdiagnosed in people with intellectual disabilities. Further studies involving assessing participants for hypertension rather than relying on recorded diagnoses are required.
Metabolic syndrome	The small amount of evidence suggests that metabolic syndrome may be more common among women than men with intellectual disabilities. Metabolic syndrome may be more common among older women with intellectual disabilities than among older women in the general population, but lower among older men with intellectual disabilities than among older men in the general population. Further research is required to confirm this.
Overweight and obesity	Female gender has been found to be the strongest risk factor for overweight/obesity status in individuals with intellectual disabilities. The prevalence of obesity and morbid obesity among women with intellectual disabilities is significantly higher than among women without intellectual disabilities.
Physical inactivity	Women with intellectual disabilities are less likely to take part in physical activity than men with intellectual disabilities and for both men and women the number meeting physical activity guidelines is extremely low.
Smoking	Men with intellectual disabilities are more likely to smoke than women with intellectual disabilities. Further research is needed to compare smoking rates among men and women with intellectual disabilities to smoking rates among the general population. Internationally, cultural differences are likely to influence smoking rates.
Low and middle income countries (LMIC)—referred to as LAMI countries in the statement	Mortality for people with intellectual disabilities is likely to be elevated in low and middle income (LAMI) countries compared to high income countries. Qualitative differences in issues related to mortality are likely to exist between LAMI and high income countries. Further research is required to identify any gender differences in relation to the mortality of people with intellectual disabilities in LAMI countries.

they wished. Optional topics are indicated with superscript a in Tables 2–4.

Respondents were also asked to select their perceived top three topic priorities for future research relating to gender and the premature deaths of people with intellectual disabilities. An open-ended question sought suggestions from respondents on how to address gaps in the evidence and a final open-ended question allowed respondents to add any additional comments they wished.

An invitation to participate in the consultation was sent by email in May 2019 to 20 researchers with expertise (defined as having a record of relevant publications in peer reviewed journals or of public health reports) relevant to the mortality of people with intellectual disabilities. All potential participants were required to communicate in writing in the English language. Potential participants were identified via the IASSIDD Health SIRG as having expertise in mortality research concerning people

with intellectual disabilities, as this SIRG is active in mortality issues. All 20 of those approached expressed an interest in taking part in the consultation and were sent a copy of the literature review and a unique personal link to the online questionnaire. Consent was obtained within Qualtrics once the respondent accessed the questionnaire via their unique link. Ethical approval for the study was granted by Lancaster University Faculty of Health and Medicine Research Ethics Committee.

### Analysis

Analyses of Likert scale responses were undertaken using IBM SPSS v23. All responses were scored on a 5-point scale: strongly disagree (1), disagree (2), neither agree nor disagree (3), agree (4), and strongly agree (5), with don't know available

as an additional option. Median scores were calculated for each question. Free text responses were exported to a Microsoft Excel database. An iterative approach was taken to analyzing free-text answers in which a list of themes was identified via reading and re-reading free-text answers and these themes were allocated to overarching themes (Braun & Clarke, 2006).

## Results

Eighteen (90%) of those approached completed the questionnaire within the timescale of the study, including one respondent who partially completed the questionnaire. Respondents were from nine countries (USA, Canada, Australia, Sweden, Germany, Finland, the UK, the Netherlands, and Ireland), with no more than four respondents from any one country. Eleven people agreed to answer optional questions on specific syndromes. Thirteen people agreed to answer optional questions on contraception, pregnancy and childbirth, and menopause. Sixteen people agreed to answer optional questions on risk factors for mortality (overweight and obesity, physical inactivity, hypertension, high cholesterol, metabolic syndrome, and smoking).

### Likert Scale Responses

The number selecting each response option and the median ratings for each question are given in Tables 2–4. The number answering “I do not know” is also provided for each question. In the results reported below, the total number of responses given excludes those who responded “I do not know” or other missing values.

**Question 1: Agreement with each summary statement (Table 2).** Results for the extent to which respondents agreed with each summary statement (see Table 1 for the summary statements) are given in Table 2. “Don’t know” responses were more common here than in response to questions about the importance of the topic or the adequacy of the evidence. One respondent noted that for some of the statements, they could not rate agreement as the statement consisted of multiple elements and they agreed with some elements but not others.

There was a high level of agreement with the topic statement on gender differences in mortality compared to the general population (“inequality in mortality rates between the population of people with intellectual disabilities and the general population is greater for females than males”), with 11 of the 18 respondents strongly agreeing and no instances of disagreement. There was also a high level of agreement with the topic statement for age at death (“the gap in life expectancy between those with intellectual disabilities and the general population is greater for females than males”), with 9 of the 18 respondents strongly agreeing and no instances of disagreement. However, for the topic statement on age trends in gender differences in mortality (“the greater inequality in mortality rates for females with intellectual disabilities is mainly a feature of younger age groups”), 5 of the 17 respondents disagreed.

For all the other topics, there was generally agreement with each summary statement, a median score of at least 4 for each topic (indicating “I agree” with each summary statement). Summary statements with the largest number of respondents “strongly agreeing” were: physical inactivity (“Women with intellectual disabilities are less likely to take part in physical activity than men with intellectual disabilities and for both men and women the number meeting physical activity guidelines is extremely low”; 11/15 respondents); cancer (“There is little evidence relating to gender and the risk of death due to cancer in people with intellectual disabilities ...”; 13/18 respondents); and low and middle income countries (LMIC) (“...Further research is required to identify any gender differences in relation to the mortality of people with intellectual disabilities in LMIC countries”; 10/16 respondents).

### Question 2: Importance of topic summarized in each summary statement (Table 3).

The topic with the greatest number of respondents “strongly agreeing” with its importance was physical inactivity (see Table 1 for the summary statement), with 14 of 16 respondents strongly agreeing. A substantial majority (13/18 respondents) strongly agreed that the following topics were important: gender differences in mortality compared to the general population, age at death, cancer (“There is little evidence relating to gender and the risk of death due to cancer in people with intellectual disabilities ...”), diabetes (“We are not aware of any evidence on gender differences in the risk of death due to diabetes among people with intellectual disabilities ...”), and bone health and fractures (“Older women with intellectual disabilities may be more at risk of fatal fracture than women in the general population ...”). There was less agreement (strongly agree 4 out of 18 respondents) regarding the importance of age trends in gender differences in mortality (see above).

### Question 3: Adequacy of evidence base for each summary statement (Table 4).

For the question “To what extent do you agree that the evidence base on this topic is adequate?,” 31 of the 33 summary statements attained a median rating of two or less, indicating respondents disagreed that the evidence base underpinning the summary statement was adequate. Only one topic attained a median rating of four, suggesting that respondents perceived the evidence base to be adequate; this was in relation to age at death.

## Priorities for Future Research

The three most important perceived priorities for future research relating to gender and the premature deaths of people with intellectual disabilities, as rated by the respondents, are given in Figure 1. “Cause-specific death rates” was the most frequently chosen main research priority, followed by “age trends in mortality compared to the general population.” “Overweight and obesity” was selected by two respondents as being the main priority and one as third priority. No other topic was selected as a main priority by more than one respondent. “Physical inactivity” and “cancer” were selected as the second or third priority



TABLE 2

Number and median of ratings for “To what extent to do you agree with this statement?” where “strongly disagree” rated 1 and “strongly agree” rated 5

Agreement with statement	Strongly disagree (1)	Disagree	Neither agree nor disagree	Agree	Strongly agree (5)	Do not know	Median
<b>Mortality</b>							
Age at death	-	-	-	9	9	0	4.5
Age trends in mortality	-	5	-	10	2	1	4
Mortality v general pop	-	-	-	7	11	0	5
<b>Health condition related to mortality</b>							
Bone health and fractures	-	1	-	6	10	1	5
Cancer	-	-	-	5	13	0	5
Cardiovascular disease	-	-	4	6	4	4	4
Dementia	-	4	2	7	2	3	4
Diabetes	-	-	3	7	7	1	4
Digestive system	-	1	1	9	6	1	4
Endocrine	-	-	2	12	2	2	4
Epilepsy	-	1	-	11	5	1	4
External causes	-	-	2	8	4	3	4
Infectious diseases	-	-	1	7	8	2	4.5
Respiratory disease	-	-	4	7	5	2	4
<b>Specific syndromes</b>							
Down syndrome <sup>a</sup>	-	-	-	7	2	1	4
Fragile X <sup>a</sup>	-	-	1	7	2	1	4
Prader Willi <sup>a</sup>	-	-	1	5	-	4	4
Rett syndrome <sup>a</sup>	-	-	-	7	2	1	4
<b>Male specific issues</b>							
Prostate cancer	-	-	-	7	7	3	4.5
Testicular cancer	-	-	-	8	3	6	4
<b>Female specific issues</b>							
Breast cancer	-	1	-	8	4	3	4
Cervical cancer	-	-	1	10	4	1	4
Contraception <sup>a</sup>	1	-	-	7	5	0	4
Menopause <sup>a</sup>	-	-	4	3	5	1	4
Ovaries and uteri cancer	-	-	1	10	2	4	4
Pregnancy and childbirth <sup>a</sup>	-	-	1	5	4	3	4
<b>Risk factors</b>							
High cholesterol <sup>a</sup>	-	-	1	7	7	0	4
Hypertension <sup>a</sup>	-	2	3	2	9	0	5
Metabolic syndrome <sup>a</sup>	-	-	1	5	6	4	4.5
Overweight and obesity <sup>a</sup>	1	-	1	4	8	2	5
Physical inactivity <sup>a</sup>	-	-	1	3	11	1	5
Smoking <sup>a</sup>	-	-	1	9	6	0	4
LMIC	-	-	1	5	10	1	5

<sup>a</sup>Section optional within online questionnaire.

Mortality v general pop, mortality compared to the general population; LMIC, low and middle income countries.

TABLE 3

Number and median of ratings for “To what extent do you agree that this is an important topic?” where “strongly disagree” rated 1 and “strongly agree” rated 5

Agreement that important topic	Strongly disagree (1)	Disagree	Neither agree nor disagree	Agree	Strongly agree (5)	Do not know	Median
<b>Mortality</b>							
Age at death	-	-	1	4	13	0	5
Age trends in mortality	-	-	2	12	4	0	4
Mortality v general pop	-	-	-	5	13	0	5
<b>Health condition related to mortality</b>							
Bone health and fractures	-	-	-	5	13	0	5
Cancer	-	-	-	5	13	0	5
Cardiovascular disease	-	-	2	9	7	0	4
Dementia	-	-	2	5	11	0	5
Diabetes	-	-	1	4	13	0	5
Digestive system	-	-	2	6	10	0	5
Endocrine	-	1	-	10	7	0	4
Epilepsy	-	-	2	9	7	0	4
External causes	-	-	3	5	8	1	4.5
Infectious diseases	-	-	3	8	7	0	4
Respiratory disease	-	-	3	8	7	0	4
<b>Specific syndromes</b>							
Down syndrome <sup>a</sup>	-	-	1	6	4	0	4
Fragile X <sup>a</sup>	-	-	3	5	3	0	4
Prader Willi <sup>a</sup>	-	-	2	5	3	1	4
Rett syndrome <sup>a</sup>	-	-	1	6	4	0	4
<b>Male specific issues</b>							
Prostate cancer	-	-	-	10	7	0	4
Testicular cancer	-	-	-	8	6	2	4
<b>Female specific issues</b>							
Breast cancer	-	-	-	6	10	1	5
Cervical cancer	-	-	1	7	9	0	5
Contraception <sup>a</sup>	-	-	-	6	7	0	5
Menopause <sup>a</sup>	-	-	1	5	7	0	5
Ovaries and uteri cancer	-	-	1	7	7	2	4
Pregnancy and childbirth <sup>a</sup>	-	-	1	5	6	1	4.5
<b>Risk factors</b>							
High cholesterol <sup>a</sup>	-	-	3	4	9	0	5
Hypertension <sup>a</sup>	-	1	3	2	10	0	5
Metabolic syndrome <sup>a</sup>	-	-	1	7	7	1	4
Overweight and obesity <sup>a</sup>	-	-	-	5	11	0	5
Physical inactivity <sup>a</sup>	-	-	1	1	14	0	5
Smoking <sup>a</sup>	-	2	3	4	7	0	4
LMIC	-	-	1	4	12	0	5

<sup>a</sup>Section optional within online questionnaire.

Mortality v general pop, mortality compared to the general population; LMIC, low and middle income countries.

by five respondents, and cardiovascular disease by three. Respiratory disease was selected as the second most important priority by two respondents, and metabolic syndrome was selected as

the second or third most important by two respondents. No other topic was chosen as a main, second, or third priority by more than one respondent.

TABLE 4

Number and median of ratings for “To what extent do you agree that the evidence base on this topic is adequate?” where “strongly disagree” rated 1 and “strongly agree” rated 5

Evidence base is adequate	Strongly disagree (1)	Disagree	Neither agree nor disagree	Agree	Strongly agree (5)	Do not know	Median
Mortality							
Age at death	1	4	1	9	3	0	4
Age trends in mortality	2	7	4	4	-	1	2
Mortality v general pop	4	2	4	6	2	0	3
Health condition related to mortality							
Bone health and fractures	3	9	2	3	1	0	2
Cancer	9	5	1	2	1	0	1.5
Cardiovascular disease	6	6	4	-	1	1	2
Dementia	4	9	4	1	-	0	2
Diabetes	6	8	3	1	-	0	2
Digestive system	7	8	1	2	-	0	2
Endocrine	7	5	3	3	-	0	2
Epilepsy	4	7	3	4	-	0	2
External causes	2	9	2	2	-	2	2
Infectious diseases	4	11	1	2	-	0	2
Respiratory disease	9	5	1	3	-	0	1.5
Specific syndromes							
Down syndrome <sup>a</sup>	3	6	-	1	1	0	2
Fragile X <sup>a</sup>	4	5	1	-	1	0	2
Prader Willi <sup>a</sup>	3	6	1	-	-	1	2
Rett syndrome <sup>a</sup>	2	6	1	-	2	0	2
Male specific issues							
Prostate cancer	6	8	1	1	1	0	2
Testicular cancer	4	7	2	1	-	3	2
Female specific issues							
Breast cancer	8	6	1	1	-	1	1.5
Cervical cancer	7	8	1	1	-	0	2
Contraception <sup>a</sup>	2	7	-	1	2	1	2
Menopause <sup>a</sup>	2	8	2	-	1	0	2
Ovaries and uteri cancer	6	7	-	2	-	2	2
Pregnancy and childbirth <sup>a</sup>	3	6	-	1	1	2	2
Risk factors							
High cholesterol <sup>a</sup>	6	6	2	-	2	0	2
Hypertension <sup>a</sup>	5	6	2	2	1	0	2
Metabolic syndrome <sup>a</sup>	3	8	2	-	2	1	2
Overweight and obesity <sup>a</sup>	2	7	2	5	-	0	2
Physical inactivity <sup>a</sup>	3	6	1	2	4	0	2
Smoking <sup>a</sup>	4	4	5	1	1	1	2
LMIC	9	3	2	1	1	1	1

<sup>a</sup>Section optional within online questionnaire.

Mortality v general pop, mortality compared to the general population; LMIC, low and middle income countries.

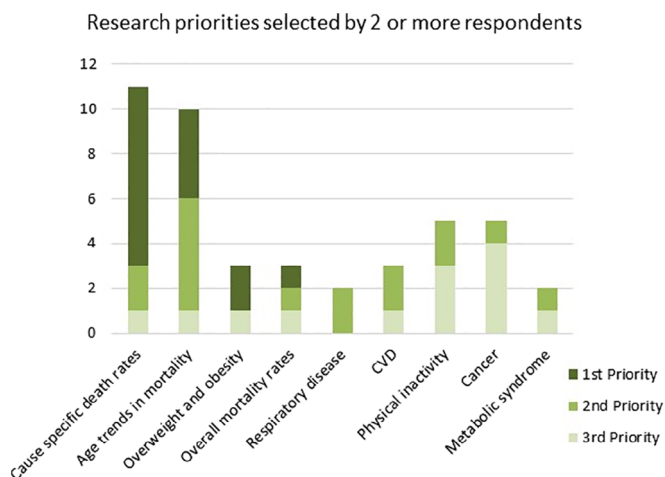


FIGURE 1

Research priorities selected as 1st, 2nd, or 3rd priority by two or more respondents.

### Themes and Subthemes

Identified themes and subthemes from participants' written comments across the questionnaire are summarized below, along with illustrative quotes. A summary of themes and subthemes is available in Table 5.

**Theme 1: Paucity of evidence.** Comments made by respondents pointed to the inadequacy of existing evidence relating to gender and the premature deaths of people with intellectual disabilities, both in terms of the quantity and quality of evidence available. Subthemes within this theme are outlined below.

#### Lack of evidence

The lack of evidence was noted by respondents as both pervasive across topics: "I think there is not much we can make bold statements about on this topic, as there is just not enough research ..." (P14) and regarding specific topics, for example, in relation to the topic "external causes" of death: "... There is a huge lack of studies on this topic" (P7).

#### Need for additional evidence

Respondents mentioned the need for additional evidence on several topics, for example: "... I think we need to understand rates of different respiratory diseases in both sexes, as they relate to death, and just generally" (P8) and: "Further research on gender differences in the risk of death from Cardio Vascular Diseases is needed" (P10).

#### Provision of additional evidence

Some respondents mentioned additional evidence to that used in the literature review, either from local services or from reports outwith the criteria for the review.

TABLE 5

Themes and subthemes from respondents' written comments

Theme	Subthemes
1: Paucity of evidence	Lack of evidence Need for additional evidence Provision of additional evidence
2: Limitations of existing evidence	Bias in study samples Small sample sizes Low rates of some health issues
3: Need for greater differentiation within studies	Subgroups, e.g., specific syndromes Type of disease Impact of multiple health problems Impact of other influencing factors
4: Explanatory issues	Need for research with an explanatory focus Suggested explanatory mechanisms Role of differential survival
5: Diagnostic issues	Presentation of condition Prevention of condition Late/missed diagnosis Screening Diagnostic overshadowing
6: Prevention	Preventable conditions Health risks at younger ages
7: Recommendations	Research recommendations Policy recommendations Other recommendations

"Saying it is 'not negligible' is an understatement. Deaths of people with learning disabilities [the common UK term for people with intellectual disabilities] are reported to our local service, and in recent years there were four due to cervical cancer. That is not in the published literature though" (P14).

"... a national report ... found that people with these disabilities died more than twice as often from breast cancer (70%) compared to women in general. In addition the cancer was found in a later stage. Unfortunately [the report is] not available in English ..." (P7).

**Theme 2: Limitations of existing evidence.** Limitations in the existing evidence base were frequently noted. While the statements were at times felt to reflect available evidence, there were concerns that the evidence base is flawed and inadequate, for example, in relation to the topic "age trends in gender differences in mortality": "... While the statement does reflect the evidence available, I have concerns about whether there is sufficient complete evidence to make this statement accurate in

practice” (P17). Subthemes within this theme are outlined below.

#### ***Bias in study samples***

Evidence on gender and mortality was noted to be limited by the bias in existing studies, for example, the extent to which they include people with mild intellectual disabilities. For example, one respondent noted that: “... Many studies do not include individuals with intellectual and developmental disabilities [IDD, a population including both people with intellectual disabilities and people with developmental disabilities without a co-occurring intellectual disability] with less severe impairments or incorrectly groups them with the general population” (P16).

#### ***Small sample sizes***

Small sample sizes were highlighted as a limitation of existing evidence, for example: “For many of these questions, I think saying evidence indicates no difference is putting it a bit too strong, as most studies are just too small to have any credibility ...” (P14).

#### ***Low rates of some health issues***

For some conditions/causes of death, low rates of occurrence were noted as a challenge to high-quality research. For example, in relation to cancer one respondent noted that: “Low rates of cancer and poor early identification make this a tough topic on which to draw conclusions” (P11) and another stated: “Nascent evidence at best on this. Often sample sizes are too small when drilling down on more specific types of cancer” (P3).

#### **Theme 3: Need for greater differentiation within studies.**

Respondents mentioned a need for greater differentiation within studies in relation to specific syndromes, specific health problems, and other influencing factors. Subthemes within this theme are outlined below.

#### ***Subgroups, for example, specific syndromes***

Comments highlighted the need to consider subgroups when studying gender and mortality, for example: “The population is heterogeneous...more on mortality rates within specific conditions is needed” (P1) and: “... We need studies where we have controlled for more common causes for (intellectual disabilities) and especially if those are syndromes with higher prevalence of comorbidity such as diabetes ...” (P7).

#### ***Type of disease***

Greater differentiation by type of disease was called for across topics. For example, in relation to respiratory disease: “... I am concerned that many of these studies, if not all, do not differentiate by type of respiratory disease, and thus many not be picking up on age related sex differences” (P3).

#### ***Impact of multiple health problems***

Studies were noted not to differentiate by comorbidities. For example, in relation to the topic “age trends in gender differences in mortality,” one respondent noted: “... Much of this evidence may not fully differentiate by comorbid developmental disabilities which could influence outcomes” (P3).

#### ***Impact of other influencing factors***

The need for studies to take into account other influencing factors was highlighted. For example, in relation to obesity and overweight: “We need better studies that control for different causes for the intellectual disabilities, medication, age ...” (P7).

**Theme 4: Explanatory issues.** Many respondents provided comments concerning potential explanations for a gender disparity in mortality among people with intellectual disabilities compared to the general population. Subthemes within this theme are outlined below.

#### ***Need for research with an explanatory focus***

The need for more research with an explanatory focus was highlighted. For example, one respondent noted: “Evidence that the difference exists is adequate. Evidence regarding the explanations for this difference is not” (P3).

#### ***Suggested explanatory mechanisms***

Possible explanatory mechanisms for the gender disparity were postulated by respondents. These included lower rates of external causes of death among men with intellectual disabilities, for example: “... males with intellectual disabilities are protected from higher risk behaviors that often result in the death of males without intellectual disabilities early in life. While not explaining all, I think this likely explains the majority of the difference” (P3). A further explanatory mechanism suggested was the difficulties women with intellectual disabilities may experience in attending to their health needs: “... It may have to do with capacity to care for self, notice problems early, attend to health, comply with treatment recommendations. All of this is impaired in women with intellectual disabilities” (P8). General inequalities experienced by women with intellectual disabilities were also suggested as a possible explanatory mechanism: “... maybe intellectual disabilities is just so low down society’s priorities that the improvements in women’s rights haven’t happened yet for women with intellectual disabilities. So in the general population, the gender gap between rights/opportunities/equality has narrowed, but in the population with intellectual disabilities, it hasn’t ...” (P14). The lifestyle of females (e.g., greater levels of physical inactivity compared to men) was also mentioned in relation to age at death: “Lifestyle of females in particular may account for the disparity” (P2). Biological mechanisms were also postulated in relation to specific syndromes.

#### ***Role of differential survival***

Another subtheme concerned differential survival. For example, in relation to dementia one respondent noted that: “I’m concerned that this statement and the comparisons are in part driven by differential survival across genders and between the general and IDD populations. In essence, the difference of who survives to an age where dementia may onset can affect this comparison” (P17).

**Theme 5: Diagnostic issues.** Comments were made in relation to diagnostic issues and the subthemes within this theme are outlined below.

#### ***Presentation of condition***

Comments pointed to the way that gender may influence the presentation of a condition and subsequent diagnosis. For

example, in relation to dementia one respondent noted that: "... I think for women, if they are quiet and good, we miss things ..." (P8). In relation to the digestive system the same respondent noted: "... how do women complain about constipation, and other types of digestive disorders" (P8).

### **Late/missed diagnosis**

Late diagnosis and the problem of conditions being missed were also raised. For example, in relation to dementia: "Late diagnosis may mean cases are missed when there are other chronic conditions" (P11). Similarly, in relation to infectious diseases one respondent noted that: "(in women) ... UTI [urinary tract infection] causes terrible pain and distress, and is often missed ..." (P8).

### **Screening**

Screening was regularly raised. For example, one respondent noted in relation to breast cancer: "Regular screening is often neglected among female persons who do not cooperate easily at the examination" (P9). The impact of screening on disease outcomes was also mentioned as unresearched, for example, in relation to testicular cancer: "Important question of whether earlier diagnosis would change survival rates" (P11).

### **Diagnostic overshadowing**

Another issue raised was that of diagnostic overshadowing. For example: "Looking at cause of death or cause for visits to the health care is problematic when cause of death for a large proportion is their diagnosis of disability such as Down syndrome" (P7).

**Theme 6: Prevention.** Prevention was mentioned across several topics. Subthemes within this theme are outlined below.

### **Preventable conditions**

Preventable conditions were regularly mentioned. For example, in relation to cervical cancer: "A condition that can be prevented and premature death avoided. It is a target area for public health: why not also target women with intellectual disabilities" (P4).

### **Health risks at younger ages**

It was noted that many health risks begin at younger ages among people with intellectual disabilities and this should be prevented. For example, in relation to obesity and overweight: "... We also know that differences in obesity are evident in adolescence from Special Olympics data. THIS IS FIXABLE ..." (P8).

**Theme 7: Recommendations.** Many respondents suggested recommendations for research, policy, and international collaboration. Subthemes within this theme are outlined below.

### **Research recommendations**

Several research recommendations focused on sources of data that could be used to examine the issue of gender and the premature deaths of people with intellectual disabilities. First, it was noted that all mainstream mortality studies should include

people with intellectual disabilities: "All mortality studies in the general population should also compare and contrast differences for people with intellectual disabilities (thereby gender differences can be examined). People with intellectual disabilities should not be excluded from mainstream mortality studies" (P4). Linked datasets and administrative datasets were also mentioned, for example: "Linked population datasets should be routinely investigated and reported ..." (P15) and: "Longitudinal studies (prospective and retrospective are needed) perhaps from administrative data sets" (P2). It was also suggested that pooling data from different countries could help address gaps in evidence: "Pooling data from different countries and jurisdictions to create a virtual minimum intellectual disabilities mortality data set" (P12). Finally, it was suggested that all studies should include analyses by gender: "We should require that every study consider sex and gender or explain why not" (P8).

Other research recommendations highlighted the need to address the limitations of the existing evidence base mentioned by respondents in previous themes, including the need for internationally consistent methodology and case definition to minimize sample bias, greater differentiation within studies (including health conditions and the nature of people's disabilities), and studies taking into account the impact of other influencing factors:

... It is important to use consistent methodology and case definition to provide additional evidence in support of the statement regarding gender differences in mortality for people with intellectual/developmental/learning disabilities compared to the general population (P10).

I think it is extremely important as we go forward ... for us to do a better job differentiating by comorbid developmental disabilities (Down syndrome, cerebral palsy, Rett's, etc.) ... (P3).

Studies need to examine the effect of gender when other covariates are controlled (P2).

... When possible, I think we need to move away from broad ICD-10 chapter codes and focus comparative analysis on cause specific codes (P3).

Specific research suggestions were also made, including studies of gender differences in health conditions related to mortality, intersectional sociological studies of society's attitudes toward men and women with intellectual disabilities, work to establish a consensus set of avoidable deaths for children and adults with intellectual disabilities, and research to develop effective interventions.

### **Policy recommendations**

A small number of policy recommendations were made. It was suggested that people with intellectual disabilities should be identified within policies as a high risk group: "... international and national data (should be used) to inform policy where men and women specifically with intellectual disabilities are identified within government policies as a high-risk group and specific targets identified ..." (P4). It was further suggested that the issue of accountability needed to be addressed: "... intellectual disabilities organisations and primary healthcare are held

accountable in addressing the continued gender differences in mortality, risk factors and delivery of such interventions ...” (P4).

#### Other recommendations

Other recommendations suggested by respondents largely concerned international collaborative action:

... international and national data to inform targeted gender specific health promotion programmes, health promotion literacy, health screening programmes and theoretically underpinned evidence-based interventions ... (P4).

... Perhaps a strong statement by WHO and other bodies [e.g.] IASSIDD/our international consortium (P15).

#### Discussion

Among 18 international experts, there was consensus that the gap in life expectancy between those with intellectual disabilities and the general population was greater for females than males, such that males and females with intellectual disabilities had broadly similar life expectancies. Both disparities in mortality rates and life expectancy attained high importance ratings and were considered to have the most adequate evidence base from the topics included in the study. In contrast, there was little agreement regarding the statement that the greater disparity in mortality rates for females with intellectual disabilities is mainly a feature of younger age groups, with little agreement regarding the importance of this topic and less agreement regarding the adequacy of the evidence base. Overall, the evidence base was generally viewed as inadequate for all other topics.

The most important priority for future research identified by respondents was examining cause-specific death rates, followed by examining age trends in mortality compared to the general population. Specific health topics regarded as important priorities for future research were: overweight and obesity, physical inactivity, cancer, cardiovascular disease, respiratory disease, and metabolic disease. The evidence as it stands does not allow robust conclusions to be drawn about the different patterns of mortality by gender for people with intellectual disabilities vs without intellectual disabilities, and the extent to which these are a function of greater inequalities experienced by women with intellectual disabilities or more similarities in the experiences of males and females with intellectual disabilities resulting in similar (premature) ages of death.

Respondents also provided wide ranging recommendations relating to gender and the premature deaths of people with intellectual disabilities. These range from recommendations regarding how to approach future research, such as the use of consistent methodology and case definition, to the need for governments to be called to account. Further evidence on gender and mortality is urgently needed; an international consensus on recommendations for future research pertaining to gender and the premature deaths of people with intellectual disabilities

would greatly assist the development of evidence-based policy and practice.

#### Study Limitations

The review on which this international expert consultation was based was limited to publications available in the English language. There was also no formal assessment of the quality of the included research. While a call for information relevant to the review was made via email networks, the review may have missed evidence from the gray literature. Respondents made a great number of detailed comments and it has not been possible to report all thematic findings in detail. For example, space did not permit the reporting of research suggestions relating to specific health topic areas and other health topic specific issues that were raised. Nonetheless, the results presented here provide the first overview of international expert opinion on the main issues in relation to gender and the premature deaths of people with intellectual disabilities.

#### Conclusion

There appears to be agreement among international experts that the inequality in mortality rates compared to the general population is greater for women than men with intellectual disabilities. However, it is clear that the evidence base on topics which might help to explain this gender disparity is lacking, with a paucity of evidence and limitations to the evidence that does exist. Further evidence on gender and mortality is urgently needed; an international consensus on recommendations for future research pertaining to gender and the premature deaths of people with intellectual disabilities would greatly assist the development of evidence-based policy and practice.

#### Acknowledgments

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#### Conflict of Interest

Laurence Taggart is an editor of JPPID. The authors report no other conflicts of interest.

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